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Complete List of Authors:	Hadi, Muhammad; University of Leeds, School of Healthcare Alldred, David ; University of Leeds, School of Healthcare Briggs, Michelle; University of Manchester, Division of Nursing, Midwifery and Social Work, School of Health Sciences, Faculty of Biology, Medicine and Health Marczewski, Kathryn; Musculoskeletal Services, St. George's Centre Closs, S.José; University of Leeds, School of Healthcare
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"Treated as a number, not treated as a person": Chronic pain patients' perceived barriers to effective pain management

Muhammad Abdul Hadi, [*1] David Phillip Alldred,[1] Michelle Briggs,[2,3] Kathryn Marczewski,[4] S. José Closs[1]

[1]School of Healthcare, University of Leeds, Leeds, UK

[2]Division of Nursing, Midwifery and Social Work, School of Health Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK

[3]Research and Innovation Division, Central Manchester University Hospitals NHS Foundation Trust, Manchester, UK

[3]Clinical Nurse Specialist, Musculoskeletal Services, St. George's Centre, Leeds, UK

***Corresponding Author**

Muhammad Abdul Hadi

Research Fellow in Applied Health Research

School of Healthcare

Baines Wing,

University of Leeds

Tel: 01133437558

Email: m.a.hadi@leeds.ac.uk

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Data Sharing: Data is available from the corresponding author upon request.

Conflict of Interest: None declared.

Running head: Experiences of chronic pain management

Abstract

Objectives: To explore chronic pain patients' views and experiences of the UK's National Health Service (NHS) to identify barriers to effective pain management.

Design: Secondary analysis of face-to-face, semi-structured qualitative interviews using thematic analysis

Setting: A community-based chronic pain clinic jointly managed by a nurse and pharmacist located in the north of England.

Participants: Nineteen adult (> 18 years age) chronic pain patients discharged from a pain clinic, with the ability to understand and speak the English language.

Results: In general, patients were highly disappointed with the quality of pain management services provided both within primary and secondary care, and consequently, were willing to seek private medical care. Barriers to effective pain management were divided into two main themes: Healthcare professional-related and Health systems-related. Three sub-themes emerged under healthcare professionals-related barriers including: a) Healthcare professionals' lack of interest and empathy b) general practitioners' (GP) lack of specialised knowledge in pain management, c) lack of communication between healthcare professionals. Three sub-themes emerged under health system-related barriers: a) long waiting time for appointments in secondary care, b) short consultation times with GPs, c) lack of an integrated multidisciplinary approach.

Conclusions: The patients expressed a clear desire for the improved provision and quality of chronic pain management services within the NHS to overcome barriers identified in this study. An integrated holistic approach based on a biopsychosocial

model is required to effectively manage pain and improve patient satisfaction. Future research should explore the feasibility and effectiveness of integrated care delivery models for chronic pain management.

Strengths and limitations of the Study:

- Qualitative research designs are best suited when patients' views and experiences are required to be explored.
- Various methods including peer-debriefing and in depth description of methods were used to ensure rigour and trustworthiness of study findings.
- The transferability of the study findings should be carefully considered as patients were recruited from one chronic pain clinic only, although patients were registered with different general practices and gave their views on NHS pain services in general.

Keywords: Barriers; Pain management; Chronic pain; Nurse; Pharmacist; Primary care

Introduction

Chronic pain is one of the leading causes of disability globally (1). The prevention and/or effective management of chronic pain remains a serious challenge for public health authorities and healthcare systems around the world. It has been estimated that chronic pain affects 100 million adults in the US (2) and 28 million in the UK (3). Compared with patients with other chronic diseases, chronic pain patients tend to have poorer quality of life and use more healthcare resources (4-6).

Effective management of chronic pain is essential to limit its interference with sleep, work, physical and emotional functioning thus reducing the humanistic, societal and economic burden associated with this condition. Unfortunately, management of chronic pain remains suboptimal within primary care (5, 7). This is primarily because primary care services are often based on a 'biomedical model' rather than a 'biopsychosocial model', the latter being appropriate given the multidimensional nature of chronic pain (8, 9). Multidisciplinary clinics based on the biopsychosocial model have been shown to be effective and cost effective (8, 9). However, long waiting times for appointments, accessibility and affordability remain a serious concern (10).

The study reported here builds further on our existing knowledge of the issues and challenges faced by chronic pain patients especially within primary care settings (11). It describes findings from secondary analysis of qualitative data obtained during a mixed-methods study (12, 13). The main findings of the mixed-methods study are described elsewhere (13). The aim of undertaking this analysis was to provide an in-depth description of patient experiences of UK's National Health Services (NHS) service

provision in relation to pain management in primary care and identify barriers related to effective pain management.

Methods:

A qualitative description (14) design consisting of semi-structured, face-to-face interviews was used in this study. Qualitative description is commonly used by health service and practice researchers (14) as it is considered the method of choice when straightforward description of patients', caregivers', relatives' or healthcare professionals' experiences with a particular phenomenon is desired (14).

Sampling and recruitment

The interviews were conducted as part of a larger mixed-methods study which evaluated the effectiveness of a NHS nurse-pharmacist managed pain clinic (12, 13). The study design and working of the clinic have been described in detail elsewhere (13, 15). Patients who were enrolled in the quantitative phase of the mixed-methods study and discharged from the clinic within the study period were invited to participate in the interviews. A combination of two sampling techniques, convenience sampling and maximum variation sampling were used to recruit patients (16). Convenience sampling was used to recruit the first five patients and the remaining 14 patients were recruited using maximum variation sampling. The framework for maximum variation was based on: baseline pain intensity, duration of chronic pain and gender. Data collection continued until achieving ‘‘Data saturation’’ – whereby no new themes emerged from the data (16). Each interview lasted between 30 and 45 minutes.

Data collection

Interviews were conducted by the first author, a research pharmacist trained in qualitative research, either in patients' homes or at the pain clinic, depending on the patients' preferences. To limit recall bias, patients were interviewed within 2 weeks of their discharge. Interviews were audio-recorded. A semi-structured interview schedule was developed based on the literature and study objectives to guide the interviewer and ensure uniformity. The interview schedule guide covered the following areas: patients' experiences of living with chronic pain (impact on physical functioning, sleep, emotions etc.); interaction with GPs/primary care physicians (PCPs) and other healthcare providers; experiences of the referral system; expectations of the pain clinic; efficacy of the service and overall experiences. Patients were also provided with an opportunity to talk about any other issue related to chronic pain that was not covered during the interview.

Data Analysis

Each interview was transcribed verbatim and transcripts were checked against the original recording for accuracy by the interviewer (MAH). Data were analysed using thematic analysis (14). Line by line coding was used to code individual transcripts and the coding framework was checked independently by two experienced qualitative researchers for validity (MB, SJC). Duplicate codes were removed and different codes were sorted into potential themes. The relevant data extracts from individual interviews were gathered within these potential themes. Old themes were reviewed and sometimes renamed in the light of the emergence of new themes. Methods such as

peer review/debriefing and providing rich thick description were used to enhance rigour and trustworthiness of study findings (16).

Results

Nineteen patients were interviewed and their sociodemographic and clinical characteristics are shown in table 1. Emerging themes were classified under two overarching barriers: Healthcare professional related-barriers and Health system-related barriers (Figure 1). Sub-themes within each of these themes are described below.

Healthcare professionals-related barriers

Healthcare professional-related barriers included: lack of interest and empathy; lack of GP's specialised knowledge in pain management; short consultation times with GPs; and lack of communication between healthcare professionals. Since chronic pain was predominantly managed in primary care, a number of the barriers in this category were related to the GPs' ability to assess and manage chronic pain (Figure 1).

a. Healthcare professionals' lack of interest and empathy

A number of patients expressed concerns over a perceived lack of interest shown by healthcare professionals, especially GPs, in listening to their problems and managing their pain. The patients felt that, as chronic pain was not a life-threatening disease (like, for example, cancer), healthcare professionals were not interested in identifying the cause of the pain.

> *"I went to my GP and was just told it's wear and tear, age, nothing we can do about it, left it at that." [P.9, 51 male]*

The patients were disappointed and felt that they were wasting their time in explaining their problem as no one was interested in listening to their problems.

"I'm not getting anywhere and I thought, oh don't bother saying anything, it's a waste of time, nobody's listening – that's what I'm trying to say." [P.6, female]

A number of the patients felt they were disbelieved and judged by healthcare professionals. They were annoyed by these attitudes and this led them to stop seeking further treatment from that particular healthcare professional.

"The second physiotherapist I saw basically told me that the pain was in my imagination. So I had one appointment with him. I'm in enough pain not to be able to tolerate people who are telling me it's not real, you know, because it is real. [P.10, female]

Patients felt that they were treated impersonally, being passed from one healthcare professional to another.

"……. because the way that they treat you is absolutely disgusting from point to point, there's no…… you're treated as a number, you're not treated as a person." [P.4, 30 male]

However, some patients praised some GPs who listened to them and showed a duty of care towards them.

"My GP is superb. He will say, what's wrong with you, like blah-blah-blah, right, what do you want me to do." [P.7, 39 male]

b. Lack of GPs' specialised knowledge in pain management

The main reason highlighted by patients, for GPs' inability to effectively manage chronic pain was a perceived lack of specialised knowledge in chronic pain management.

"…..According to them [GPs] all they could do was give me paracetamol, and the best was co-codamol." [Pt.9, 51 years old male] [P.12, female]

"I'm not saying my GP isn't qualified but he is a general practitioner, he's not a consultant and he's not specialised in that area." [P.6, 58 years old female]

A few of the patients also felt that this lack of specialised knowledge was used as an excuse by the GPs to refer to the physiotherapist without establishing whether the patients actually needed physiotherapy or not.

"I think the GP finds it an easy… she doesn't know… it's the easy answer to shove you to the physio and let them have a look at you and then see what bounces back out of that." [P.4, male]

Patients viewed GPs as having limited therapeutic options, with their approach towards pain management being confined to prescribing a range of painkillers, irrespective of whether the patients were gaining any benefit or not.

"He'll just keep giving me tablets. He doesn't feel there's anywhere else to go as regards trying to find out what it is." [P.3, male]

c. *Lack of communication between healthcare professionals*

Since the patients were referred to various specialists, they were concerned about the lack of communication between the different healthcare professionals, which led to inconsistency in the approach towards pain management.

> *"I think you tend to see everybody in isolation. So the physio will refer and they will write a little letter and they will refer to a podiatrist. But then the podiatrist kind of sees the problem from such a different light that they're not really communicating with each other ……".[P.1, female]*

The patients felt that a number of unnecessary referrals were made due to the lack of effective communication between healthcare professionals.

> *"I went to the doctors, it's nothing. Tennis elbow, then it was arthritis, then it wasn't arthritis, then it was because of a previous injury. I came here, the physiotherapist looked at the x-ray and couldn't understand why I'd been referred here." [P. 9, male]*

In some instances the lack of communication led to a clash of opinions between the healthcare professionals and left the patient confused about their diagnosis.

> *"I was caught up in a bit of a battle between them two [Rheumatologist and Orthopaedic surgeon] because the rheumatologist was saying, no it's not a rheumatology problem and the orthopaedic guy was saying, well we believe it is." [P.15, male]*

Healthcare system-related barriers

Healthcare system related barriers included long waiting time for appointments in secondary care and the lack of a holistic approach.

a. Short consultation time with GPs

Another problem frequently stated by patients was the short consultation time with GPs. This meant that the GPs could not listen to the patient's full story and therefore could not design an individualised therapeutic plan to meet their needs.

> *"It's the running of the GPs basically, we're not getting heard [Pause], patients aren't getting heard and listened to. There's not enough time [P.6, female]*

> *"No sadly I don't think the GPs have enough time to look at each individual and to go through their medical history to see if they can tweak it here and there to help that patient. Sadly they haven't" [P.12, female]*

In some cases, the patients felt that due to the limited consultation time, GPs just prescribed medicines as requested by them without obtaining a full history, putting them at high risk of experiencing an adverse or even life threatening event.

> *"The GP was worried about the high blood pressure but didn't take time to look at the medication she'd actually put me on, whereas the pharmacist pointed it out to her. Potentially according to the pharmacist, for three months, I was at high risk of having a stroke." [P. 9, male]*

b. Long waiting time for appointments in secondary care

The patients were concerned over the long waiting times not only for appointments with consultants but also for scans, x-rays and other tests. The long waiting time delayed the whole care process.

> *"You're going round the houses to get back to where you want to be. It takes a long time, it does take a long time." [P. 3, male]*

> *"I was brought up to think that the Health Service would provide everything, but it doesn't, not quickly enough."[P. 5, female]*

Since the patients were not happy with the long waiting time for the appointments in secondary care, they expressed their desire to go for private treatment, provided that they had the funds to meet the cost.

> *"……if I could afford it I'd go private, put it that way." [P. 4, male]*

Patients who were able to afford it went on to seek care from the private sector and felt that the service provided there was much better than the NHS.

> *"I find the private sector, you know, service is much better. I do, I've found the NHS physio not very… [Pauses], if you are paying for treatment it is better, let's face it." [P.11, female]*

Since the patients, being tax payers, had already paid into the NHS, they expected a good service from it. They were annoyed by the fact that they perceived the treatment was in fact better in the private sector, and they had to pay again to obtain this good service.

"You wait so long in the [National] Health Service. But I had no alternative really except pay to see somebody, and that really rankles me, I don't want to do that. Because I've paid into it, haven't I? And my husband all these years." [P. 5, female]

c. Lack of integrated multidisciplinary approach

The set-up and the working of chronic pain management services in the NHS was seen as a hindrance in delivering integrated holistic care to patients.

> *"Within the NHS, every individual is great and they work really hard and they're really supportive, but they seem to be very caught in their little boxes and can't, or aren't allowed to, step outside them to maybe provide a more effective solution sometimes." [P. 1, female]*

Since chronic pain has a multidimensional impact on patients' lives, a unidimensional approach towards its management based on the bio-medical model may not achieve optimum outcomes. The patients felt that they were not managed as a whole, but that healthcare professionals instead focused on only one of the affected areas or joints.

> *"He was not interested in any other joints, just the left elbow and I wanted them to look at all." [P. 9, male]*

The patients stressed the need for a collaborative approach and were frustrated with the current situation feeling that perhaps the NHS services were not willing to make necessary reforms in order to improve chronic pain management.

"As well as the physical pain it can cause emotional problems and I think it's important to have a service where kind of all of that can be addressed together." [P. 18, female]

Discussion

The aim of this study was to explore chronic pain patients' perspectives on the barriers hindering the effective delivery of quality pain management services. Identifying such barriers could facilitate healthcare professionals and policy makers ability to design and implement strategies to improve delivery of pain management services. This is especially important in front-line primary care settings, as access to adequate therapy has been declared to be a human right by various international resolutions (17,18).

In this study various healthcare professional and health system-related barriers have been highlighted. In general, patients expressed considerable dissatisfaction with the quality of care provided by the NHS. However, it should be noted that patient satisfaction is primarily determined by patient expectations (19). A mismatch between patients' expectations and treatment outcome can lead to dissatisfaction. A systematic review reported that the best pain reduction intervention reduces pain, on average, only by 30% in about half of treated patients, meaning patients expecting cure or substantial reductions in pain are likely to be dissatisfied (20). Therefore, managing patients' expectations before and during treatment is critical in ensuring their satisfaction.

A common perception existed among patients that GPs lacked the specialised knowledge needed to manage chronic pain effectively. In studies from the UK and US, GPs/primary care providers (PCPs) have described helplessness and dissatisfaction

with their own ability to manage chronic pain patients (21-23). This lack of confidence may be explained by inadequate coverage of chronic pain in undergraduate medical curricula, highlighted in studies from the Europe and US (24, 25). Furthermore, significant increases in UK GPs' workload due to funding cuts in primary care services and difficulties retaining GPs within the NHS might also be compromising GPs' ability to effectively manage chronic pain (26). Between 2010/11 and 2014/15 face-to-face and telephone consultations grew by 13 and 63 percent, respectively. However, the GP workforce grew by only 4.75% during the same period (26). The ageing population, increase in the number of patients with multimorbidity and growing patient expectations are exacerbating these workload pressures (26).

A key concern expressed by patients was poor patient-professional partnerships due to lack of trust, empathy and communication. For patients with long term conditions, effective patient-physician relations can improve patients' health (27) and encourage self-management, key for chronic pain management. The lack of trust between patients and doctors may have negative impact on patient outcomes (27-29). Another key issue highlighted by the patients was the lack of interdisciplinary chronic pain services within the NHS. A need to reform chronic pain services within the NHS was also emphasised in order to facilitate the effective delivery of quality services. The UK's National Pain Audit found that of the 204 pain services evaluated, only 40% of clinics in England met the minimum criteria for multidisciplinary clinics by having a psychologist, a physiotherapist and a physician (30). The clinical and cost effectiveness of multidisciplinary clinics have been well documented in the literature (8,9), and therefore

access to and affordability of multidisciplinary clinics should be made a priority to improve chronic pain management.

Patients were also concerned about the long waiting time for consultations in secondary care. The waiting time for six months or more from the time of referral to treatment is associated with a worsening of health-related quality of life and psychological wellbeing (31). The International Association for the Study of Pain (IASP) Task Force on Wait Times has recommended waiting times for urgent or semi-urgent and routine appointments to be within four and eight weeks, respectively (32). In the UK, prior to the publication of the core standards of pain management services by the Faculty of Pain Medicine, Royal College of Anaesthetics (33), in 2015, generic waiting times standards, usually 18 weeks, were being followed as reported in the National Pain Audit (30). The patients also felt that the lack of communication between healthcare professionals led to unnecessary referrals, adding to patients' frustration. This also partly contributed to the long waiting time for appointments in secondary care.

There are some limitations to our research findings. Firstly, since these findings have been drawn from the secondary analysis of qualitative data which was collected as part of a mixed-methods study, some of the barriers might not have been identified as the interview guide was not exclusively developed to explore barriers to effective pain management. However, as mentioned earlier, the interview guide had questions related to patients' experiences of healthcare services and interactions with healthcare professionals. Secondly, the generalisability/ transferability of study findings should be carefully considered as the data were collected from the patients discharged from a single community-based pain clinic and therefore may not necessarily reflect

experiences of chronic pain patients living in other UK's cities. However, the patients were referred to the pain clinic by different general practices within the catchment area. Furthermore, the sample was quite diverse in terms of chronic pain conditions, duration of chronic pain, pain sites and

Implications for practice and policy

The study findings have highlighted a perceived need to improve quality and delivery of healthcare services for chronic pain patients. Ideally, a national action plan involving all key stakeholders should be developed with the aim of improving access to and delivery of pain services within the National Health Service. Since chronic pain is primarily managed within primary care, there is a need to increase resources in this setting as a first step. Given the high workload for GPs, other healthcare professionals, such as nurses and pharmacists could be engaged in greater numbers in chronic pain management within primary care settings. Based on the findings of the present study and previously published literature, areas for improvement in terms of chronic pain management service delivery include, but not limited to: improving GPs' capacity to manage pain; engaging patients in decision making and promoting self-management; developing evidence based referral guidelines; improving communication between healthcare professionals and integrating existing services; and developing multidisciplinary pain clinics.

Conclusion:

The present study has identified a number of barriers to effective management of chronic pain. Given that access to adequate pain relief is a human right (17, 18), health policy makers should recognise suboptimal management of chronic pain as a serious

public health issue and design multifaceted strategy to improve quality and delivery of chronic pain services. Identifying barriers should be seen as the first step to designing more effective chronic pain services. Without having a clear vision, political will, and chronic pain as research priority, the current situation is unlikely to improve.

Ethics

Ethical approval was obtained from the local NHS ethics committee (Ref. No. 11/YH/0415).

Author contribution:

MAH conceived the idea. MAH and KM recruited patients. MAH analysed data under the supervision of MB, DPA and SJC. MAH prepared the first draft which was revised with intellectual input by MB, DPA and SJC. All authors have read and approved the final version.

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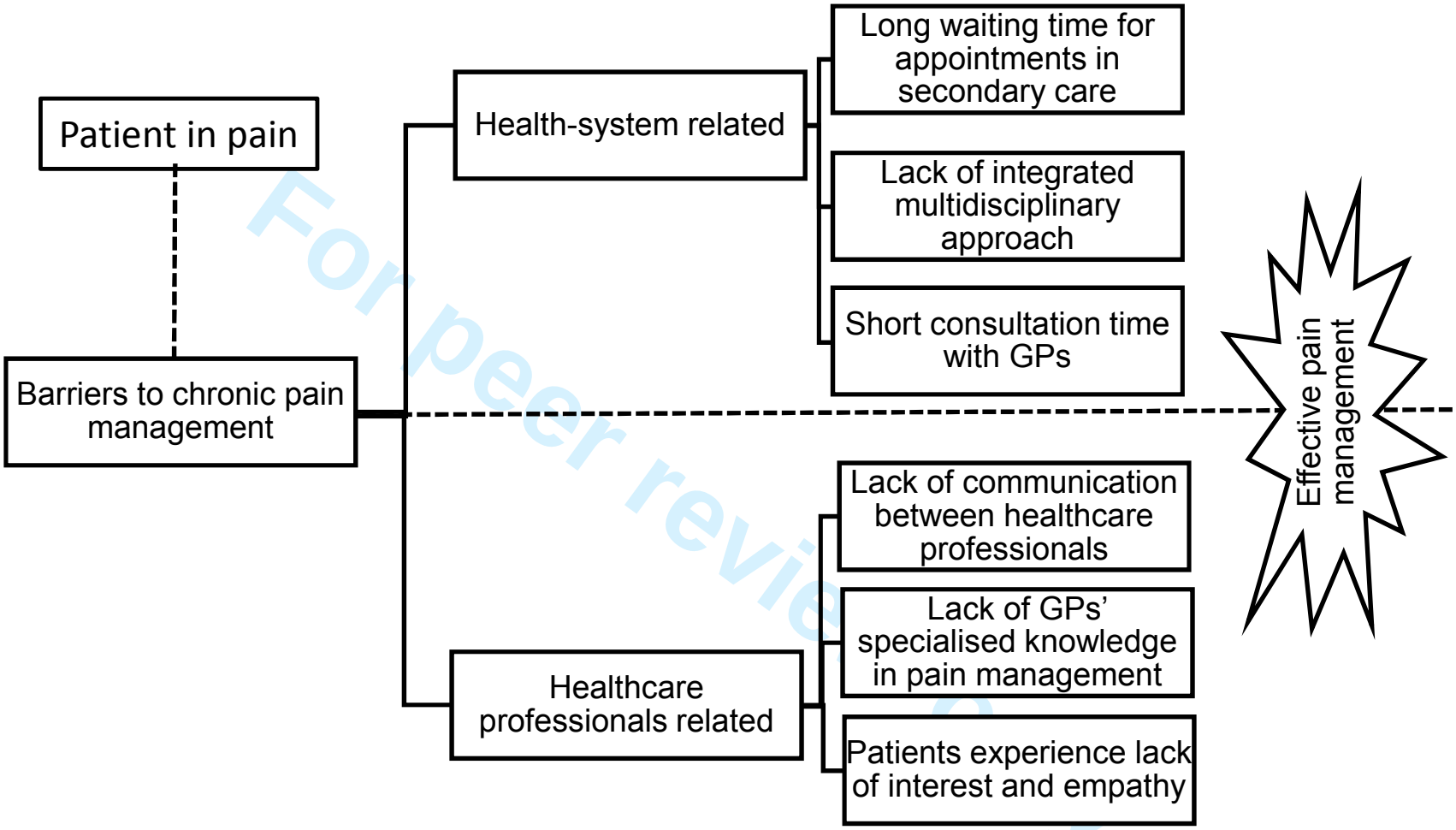
Table 1. Sociodemographic characteristics of the patients. Adapted and modified from (13)

ID	Age (Years)	Gender	Chronic pain duration in Years	Pain intensity (baseline)
P.1	36	Female	5-10	5
P. 2	49	Male	5-10	5
P. 3	63	Male	5-10	5
P. 4	30	Male	5-10	6
P. 5	74	Female	< 1	0
P. 6	58	Female	> 10	7
P. 7	39	Male	1- 3	7
P. 8	40	Female	< 1	7
P. 9	51	Male	3-5	10
P. 10	54	Female	3-5	7
P. 11	44	Female	1-3	5
P. 12	39	Female	> 1	8
P. 13	54	Male	5-10	10
P. 14	64	Female	> 10	5
P. 15	55	Male	3-5	9
P. 16	54	Female	1-3	6
P. 17	48	Female	>10	4
P. 18	27	Female	1-3	5
P. 19	47	Male	>10	7



Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Methods (page 7)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Methods (page 7)
3. Occupation	What was their occupation at the time of the study?	Methods (page 7)
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	Methods (page 7)
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods (page 7)
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods (page 7)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods (page 6)
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods (page 6)
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods (page 6)
12. Sample size	How many participants were in the study?	Results (page 6)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A

Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods (page 6)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Results (page 25)
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods (page 7)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods (page 7)
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	Methods (page 6)
22. Data saturation	Was data saturation discussed?	Methods (page 6)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Methods (page 7)
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods (page 7)
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results (page 8-14)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Discussion (page 15-16)
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results (page 8-14)
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A

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"Treated as a number, not treated as a person": a qualitative exploration of chronic pain patients' perceived barriers to effective pain management

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"Treated as a number, not treated as a person": a qualitative exploration of chronic pain patients' perceived barriers to effective pain management

Muhammad Abdul Hadi, [*1] David Phillip Alldred,[1] Michelle Briggs,[2,3] Kathryn Marczewski,[4] S. José Closs[1]

[1]School of Healthcare, University of Leeds, Leeds, UK

[2]Division of Nursing, Midwifery and Social Work, School of Health Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK

[3]Research and Innovation Division, Central Manchester University Hospitals NHS Foundation Trust, Manchester, UK

[3]Clinical Nurse Specialist, Musculoskeletal Services, St. George's Centre, Leeds, UK

***Corresponding Author**

Muhammad Abdul Hadi

Research Fellow in Applied Health Research

School of Healthcare

Baines Wing,

University of Leeds

Tel: 01133437558

Email: m.a.hadi@leeds.ac.uk

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Running head: Experiences of chronic pain management

Abstract

Objectives: To identify barriers to effective pain management encountered by chronic pain patients within the UK's National Health Service (NHS).

Design: Secondary analysis of face-to-face, semi-structured qualitative interviews using thematic analysis

Setting: A community-based chronic pain clinic jointly managed by a nurse and pharmacist located in the north of England.

Participants: Nineteen adult (> 18 years age) chronic pain patients discharged from a pain clinic, with the ability to understand and speak the English language.

Results: In general, patients were highly disappointed with the quality of pain management services provided both within primary and secondary care, and consequently, were willing to seek private medical care. Barriers to effective pain management were divided into two main themes: Healthcare professional-related and Health systems-related. Three sub-themes emerged under healthcare professionals-related barriers including: a) Healthcare professionals' lack of interest and empathy b) general practitioners' (GP) lack of specialised knowledge in pain management, c) lack of communication between healthcare professionals. Three sub-themes emerged under health system-related barriers: a) long waiting time for appointments in secondary care, b) short consultation times with GPs, c) lack of an integrated multidisciplinary approach.

Conclusions: The patients expressed a clear desire for the improved provision and quality of chronic pain management services within the NHS to overcome barriers identified in this study. An integrated holistic approach based on a biopsychosocial

model is required to effectively manage pain and improve patient satisfaction. Future research should explore the feasibility, effectiveness and cost-effectiveness of integrated care delivery models for chronic pain management within primary care.

Strengths and limitations of the Study:

- Qualitative research designs are best suited when patients' views and experiences are required to be explored.
- Various methods including peer-debriefing and in depth description of methods were used to ensure rigour and trustworthiness of study findings.
- The transferability of the study findings should be carefully considered as patients were recruited from one chronic pain clinic only, although patients were registered with different general practices and gave their views on NHS pain services in general.

Keywords: Barriers; Pain management; Chronic pain; Primary care; General Practitioners

Introduction

Chronic pain is one of the leading causes of disability globally (1). The prevention and/or effective management of chronic pain remains a serious challenge for public health authorities and healthcare systems around the world. It has been estimated that chronic pain affects 100 million adults in the US (2) and 28 million in the UK (3). Compared with patients with other chronic diseases, chronic pain patients tend to have poorer quality of life and use more healthcare resources (4-6).

Effective management of chronic pain is essential to limit its interference with sleep, work, physical and emotional functioning thus reducing the humanistic, societal and economic burden associated with this condition. Unfortunately, management of chronic pain remains suboptimal within primary care (5, 7). This is primarily because primary care services are often based on a 'biomedical model' rather than a 'biopsychosocial model', the latter being appropriate given the multidimensional nature of chronic pain (8, 9). Multidisciplinary clinics based on the biopsychosocial model have been shown to be effective and cost effective (8, 9). However, long waiting times for appointments, accessibility and affordability remain a serious concern (10).

The study reported here builds further on our existing knowledge of the issues and challenges faced by chronic pain patients especially within primary care settings (11). It describes findings from secondary analysis of qualitative data obtained during a mixed-methods study (12, 13). The main findings of the mixed-methods study are described elsewhere (13). The aim of undertaking this analysis was to identify barriers to effective pain management experienced by chronic pain patients within the UK's National Health Services (NHS).

Methods:

A qualitative description (14) design consisting of semi-structured, face-to-face interviews was used in this study. Qualitative description is commonly used by health service and practice researchers (14) as it is considered the method of choice when straightforward description of patients', caregivers', relatives' or healthcare professionals' experiences with a particular phenomenon is desired (14).

Sampling and recruitment

The interviews were conducted as part of a larger mixed-methods study which evaluated the effectiveness of a NHS nurse-pharmacist managed pain clinic (12, 13). The study design and working of the clinic have been described in detail elsewhere (13, 15). Patients who were enrolled in the quantitative phase of the mixed-methods study and discharged from the clinic within the study period were invited to participate in the interviews. A combination of two sampling techniques, convenience sampling and maximum variation sampling were used to recruit patients (16). Convenience sampling was used to recruit the first five patients and the remaining 14 patients were recruited using maximum variation sampling. The framework for maximum variation was based on: baseline pain intensity, duration of chronic pain and gender. Data collection continued until achieving ‘‘Data saturation’’ – whereby no new themes emerged from the data (16). Each interview lasted between 30 and 45 minutes. Written informed consent was obtained from all the study participants prior to the interview.

Data collection

Interviews were conducted by the first author, a research pharmacist trained in qualitative research, either in patients' homes or at the pain clinic, depending on the patients' preferences. To limit recall bias, all patients were interviewed within 2 weeks of their discharge from the clinic. Interviews were audio-recorded. A semi-structured interview schedule (Supplementary file 1) was developed based on the literature and study objectives to guide the interviewer and ensure uniformity. The interview schedule guide covered the following areas: patients' experiences of living with chronic pain (impact on physical functioning, sleep, emotions etc.); interaction with GPs/primary care physicians (PCPs) and other healthcare providers; experiences of the referral system; expectations of the pain clinic; efficacy of the service and overall experiences. Patients were also provided with an opportunity to talk about any other issue related to chronic pain that was not covered during the interview.

Data Analysis

Data were analysed using thematic analysis (14). A six-step process proposed by Braun and Clarke was used to guide the data analysis (17). Each interview was transcribed verbatim and transcripts were checked against the original recording for accuracy by the interviewer (MAH). This also allowed him to familiarize himself with the data. Line by line coding was used to code individual transcripts and the coding framework was checked independently by two experienced qualitative researchers for validity (MB, SJC). Duplicate codes were removed and different codes were sorted into potential themes. The relevant data extracts from individual interviews were gathered within these potential themes. Old themes were reviewed and sometimes renamed in the light of the emergence of new themes. Methods such as peer review/debriefing and

providing rich thick description were used to enhance rigour and trustworthiness of study findings (16).

Results

Nineteen patients were interviewed and their sociodemographic and clinical characteristics are shown in table 1. Emerging themes were classified under two overarching barriers: Healthcare professional related-barriers and Health system-related barriers (Figure 1). Sub-themes within each of these themes are described below, without any specific hierarchy/order.

Healthcare professionals-related barriers

Healthcare professional-related barriers included: lack of interest and empathy; lack of GP's specialised knowledge in pain management and lack of communication between healthcare professionals. Since chronic pain was predominantly managed in primary care, a number of the barriers in this category were related to the GPs' ability to assess and manage chronic pain (Figure 1).

a. Healthcare professionals' lack of interest and empathy

A number of patients expressed concerns over a perceived lack of interest shown by healthcare professionals, especially GPs, in listening to their problems and managing their pain. The patients felt that, as chronic pain was not a life-threatening disease (like, for example, cancer), healthcare professionals were not interested in identifying the cause of the pain. The patients were disappointed and felt that they were wasting their time in explaining their problem as no one was interested in listening to their problems. A few of the patients felt that rheumatologists were only interested in listening to their

initial problems, but not to their other ongoing problems, which sometimes might have been of more importance to the patients.

"I went to my GP and was just told it's wear and tear, age, nothing we can do about it, left it at that." [P.9, 51 male]

"And then from rheumatology they don't listen to you, they don't… they listen to the initial problem and then they just do what they want to do." [Pt. 4, 30 years old male]

Some patients felt that the GPs did not appreciate the negative impact of chronic pain on their daily lives and were very frustrated. A number of the patients felt they were disbelieved and judged by healthcare professionals. They were annoyed by these attitudes and this led them to stop seeking further treatment from that particular healthcare professional. Patients felt that they were treated impersonally, being passed from one healthcare professional to another.

"The second physiotherapist I saw basically told me that the pain was in my imagination. So I had one appointment with him. I'm in enough pain not to be able to tolerate people who are telling me it's not real, you know, because it is real. [P.10, female]

"……. because the way that they treat you is absolutely disgusting from point to point, there's no…… you're treated as a number, you're not treated as a person." [P.4, 30 male]

However, some patients praised some GPs who listened to them and showed a duty of care towards them.

"… I don't feel as they've [GPs] just been giving me anything just to get rid of me, no they've been good."[Pt.16, 54 years old female]

b. Lack of GPs' specialised knowledge in pain management

The main reason highlighted by patients, for GPs' inability to effectively manage chronic pain was a perceived lack of specialised knowledge in chronic pain management. The patients felt that the GPs do not have the right qualifications and skills to effectively manage chronic pain. Patients viewed GPs as having limited therapeutic options, with their approach towards pain management being confined to prescribing a range of painkillers, irrespective of whether the patients were gaining any benefit or not.

"I'm not saying my GP isn't qualified but he is a general practitioner, he's not a consultant and he's not specialised in that area." [P.6, 58 years old female]

"…..According to them [GPs] all they could do was give me paracetamol, and the best was co-codamol." [Pt.9, 51 years old male] [P.12, female]

A few of the patients also felt that this lack of specialised knowledge was used as an excuse by the GPs to refer to the physiotherapist without establishing whether the patients actually needed physiotherapy or not.

"I think the GP finds it an easy… she doesn't know… it's the easy answer to shove you to the physio and let them have a look at you and then see what bounces back out of that." [P.4, male]

c. Lack of communication between healthcare professionals

Since the patients were referred to various specialists, they were concerned about the lack of communication between the different healthcare professionals, which often led to inconsistency in their approach towards pain management. The patients felt that a number of unnecessary referrals were made due to the lack of effective communication between healthcare professionals. These unnecessary referrals wasted both time and money and added to patients' frustration.

"I think you tend to see everybody in isolation. So the physio will refer and they will write a little letter and they will refer to a podiatrist. But then the podiatrist kind of sees the problem from such a different light that they're not really communicating with each other ……".[P.1, female]

"I went to the doctors, it's nothing. Tennis elbow, then it was arthritis, then it wasn't arthritis, then it was because of a previous injury. I came here, the physiotherapist looked at the x-ray and couldn't understand why I'd been referred here." [P. 9, male]

In some instances the lack of communication led to a clash of opinions between the healthcare professionals and left the patient confused about their diagnosis.

"I was caught up in a bit of a battle between them two [Rheumatologist and Orthopaedic surgeon] because the rheumatologist was saying, no it's not a rheumatology problem and the orthopaedic guy was saying, well we believe it is." [P.15, male]

Healthcare system-related barriers

Healthcare system related barriers included: short consultation time with GPs; long waiting time for appointments in secondary care, and the lack of a holistic approach.

a. Short consultation time with GPs

Another problem frequently stated by patients was the short consultation time with GPs. This meant that the GPs could not listen to the patient's full story and therefore could not design an individualised therapeutic plan to meet their needs.

"It's the running of the GPs basically, we're not getting heard [Pause], patients aren't getting heard and listened to. There's not enough time [P.6, female]

"No sadly I don't think the GPs have enough time to look at each individual and to go through their medical history to see if they can tweak it here and there to help that patient. Sadly they haven't" [P.12, female]

In some cases, the patients felt that due to the limited consultation time, GPs just prescribed medicines as requested by them without obtaining a full history, putting them at high risk of experiencing an adverse or even life threatening event.

"The GP was worried about the high blood pressure but didn't take time to look at the medication she'd actually put me on, whereas the pharmacist pointed it out to her. Potentially according to the pharmacist, for three months, I was at high risk of having a stroke." [P. 9, male]

b. Long waiting time for appointments in secondary care

The patients were concerned over the long waiting times not only for appointments with consultants but also for scans, x-rays and other tests. The long waiting time delayed the whole care process. The patients felt that there were too many potentially avoidable, steps in the referral process, which contributed to their dissatisfaction with the service that they received from the NHS. In some instances, the patients remained for a long time under the care of their GPs without making any noticeable progress in terms of pain relief before being referred to a consultant/pain management service.

"You're going round the houses to get back to where you want to be. It takes a long time, it does take a long time." [P. 3, male]

"I was brought up to think that the Health Service would provide everything, but it doesn't, not quickly enough."[P. 5, female]

Since the patients were not happy with the long waiting time for the appointments in secondary care, they expressed their desire to go for private treatment, provided that they had the funds to meet the cost.

"……if I could afford it I'd go private, put it that way." [P. 4, male]

Patients who were able to afford it went on to seek care from the private sector and felt that the service provided there was much better than the NHS. As the patients had already paid into the NHS as taxpayers, they expected a good service from it. They were annoyed by the fact that they perceived the treatment was in fact better in the private sector, and they had to pay again to obtain this good service.

"I find the private sector, you know, service is much better. I do, I've found the NHS physio not very… [Pauses], if you are paying for treatment it is better, let's face it." [P.11, female]

"You wait so long in the [National] Health Service. But I had no alternative really except pay to see somebody, and that really rankles me, I don't want to do that. Because I've paid into it, haven't I? And my husband all these years." [P. 5, female]

c. Lack of integrated multidisciplinary approach

The set-up and the working of chronic pain management services in the NHS was seen as a hindrance in delivering integrated holistic care to patients. As chronic pain has a multidimensional impact on patients' lives, a unidimensional approach towards its management based on the bio-medical model may not achieve optimum outcomes. The patients felt that they were not managed as a whole, but that specialists instead focused on only one of the affected areas or joints. Therefore, there was not only the lack of a

holistic approach in terms of the working and integration of chronic pain services but also in terms of management of chronic pain patients.

"Within the NHS, every individual is great and they work really hard and they're really supportive, but they seem to be very caught in their little boxes and can't, or aren't allowed to, step outside them to maybe provide a more effective solution sometimes." [P. 1, female]

"He was not interested in any other joints, just the left elbow and I wanted them to look at all." [P. 9, male]

The patients stressed the need for a collaborative approach and believed that structural reforms were needed within the NHS so that it could better serve the needs of chronic pain patient population. However, the patients felt that the current situation of pain management services is unlikely to improve as the NHS is not willing to spend money to make the necessary reforms to improve chronic pain management.

"As well as the physical pain it can cause emotional problems and I think it's important to have a service where kind of all of that can be addressed together." [P. 18, female]

"I don't know whether that's a cost thing, whether arthritis is not a sexy disease like cancer or other things that the NHS want to throw money at." [Pt. 9, 51 years old male]

Discussion

The aim of this study was to explore chronic pain patients' perspectives on the barriers hindering the effective delivery of quality pain management services. Identifying such barriers could facilitate healthcare professionals and policy makers ability to design and implement strategies to improve delivery of pain management services. This is especially important in front-line primary care settings, as access to adequate therapy has been declared to be a human right by various international resolutions (18,19).

In this study various healthcare professional and health system-related barriers have been highlighted. Since chronic pain is primarily managed within primary care, a number of themes revolved around GPs' ability to manage pain. In general, patients expressed considerable dissatisfaction with the quality of care provided by the NHS. However, it should be noted that patient satisfaction is primarily determined by patient expectations (20). A mismatch between patients' expectations and treatment outcome can lead to dissatisfaction. A systematic review reported that the best pain reduction intervention reduces pain, on average, only by 30% in about half of treated patients, meaning patients expecting cure or substantial reductions in pain are likely to be dissatisfied (21). Therefore, managing patients' expectations before and during treatment is critical in ensuring their satisfaction.

A common perception existed among patients that GPs lacked the specialised knowledge needed to manage chronic pain effectively. In studies from the UK and US, GPs/primary care providers (PCPs) have described helplessness and dissatisfaction with their own ability to manage chronic pain patients (22-24). This lack of confidence

may be explained by inadequate coverage of chronic pain in undergraduate medical curricula, highlighted in studies from the Europe and US (25, 26). Furthermore, significant increases in UK GPs' workload due to funding cuts in primary care services and difficulties retaining GPs within the NHS might also be compromising GPs' ability to effectively manage chronic pain (27). Between 2010/11 and 2014/15 face-to-face and telephone consultations grew by 13 and 63 percent, respectively. However, the GP workforce grew by only 4.75% during the same period (27). The ageing population, increase in the number of patients with multimorbidity and growing patient expectations are exacerbating these workload pressures (27).

A key concern expressed by patients was poor patient-professional partnerships due to lack of trust, empathy and communication. For patients with long term conditions, effective patient-physician relations can improve patients' health (28) and encourage self-management, key for chronic pain management. The lack of trust between patients and doctors may have negative impact on patient outcomes (28-30). Another key issue highlighted by the patients was the lack of interdisciplinary chronic pain services within the NHS. A need to reform chronic pain services within the NHS was also emphasised in order to facilitate the effective delivery of quality services. The UK's National Pain Audit found that of the 204 pain services evaluated, only 40% of clinics in England met the minimum criteria for multidisciplinary clinics by having a psychologist, a physiotherapist and a physician (31). The clinical and cost effectiveness of multidisciplinary clinics have been well documented in the literature (8,9), and therefore access to and affordability of multidisciplinary clinics should be made a priority to improve chronic pain management.

Patients were also concerned about the long waiting time for consultations in secondary care. The waiting time for six months or more from the time of referral to treatment is associated with a worsening of health-related quality of life and psychological wellbeing (32). The International Association for the Study of Pain (IASP) Task Force on Wait Times has recommended waiting times for urgent or semi-urgent and routine appointments to be within four and eight weeks, respectively (33). In the UK, prior to the publication of the core standards of pain management services by the Faculty of Pain Medicine, Royal College of Anaesthetics (34), in 2015, generic waiting times standards, usually 18 weeks, were being followed as reported in the National Pain Audit (31). The patients also felt that the lack of communication between healthcare professionals led to unnecessary referrals, adding to patients' frustration. This also partly contributed to the long waiting time for appointments in secondary care.

There are some limitations to our research findings. Firstly, since these findings have been drawn from the secondary analysis of qualitative data which was collected as part of a mixed-methods study, some of the barriers might not have been identified as the interview guide was not exclusively developed to explore barriers to effective pain management. However, as mentioned earlier, the interview guide had questions related to patients' experiences of healthcare services and interactions with healthcare professionals. Secondly, the generalisability/ transferability of study findings should be carefully considered as the data were collected from the patients discharged from a single community-based pain clinic and therefore may not necessarily reflect experiences of chronic pain patients living in other UK's cities. However, the patients were referred to the pain clinic by different general practices within the catchment area.

Furthermore, the sample was quite diverse in terms of chronic pain conditions, duration of chronic pain, pain sites and

Implications for practice and policy

The study findings have highlighted a perceived need to improve quality and delivery of healthcare services for chronic pain patients. Ideally, a national action plan involving all key stakeholders should be developed with the aim of improving access to and delivery of pain services within the National Health Service. Since chronic pain is primarily managed within primary care, there is a need to increase resources in this setting as a first step. Given the high workload for GPs, other healthcare professionals, such as nurses and pharmacists could be engaged in greater numbers in chronic pain management within primary care settings. Based on the findings of the present study and previously published literature, areas for improvement in terms of chronic pain management service delivery include, but not limited to: improving GPs' capacity to manage pain; engaging patients in decision making and promoting self-management; developing evidence based referral guidelines; improving communication between healthcare professionals and integrating existing services; and developing multidisciplinary pain clinics.

Conclusion:

The present study has identified a number of barriers to effective management of chronic pain. Given that access to adequate pain relief is a human right (18, 19), health policy makers should recognise suboptimal management of chronic pain as a serious public health issue and design multifaceted strategy to improve quality and delivery of chronic pain services. Identifying barriers should be seen as the first step to designing

more effective chronic pain services. Without having a clear vision, political will, and chronic pain as research priority, the current situation is unlikely to improve.

Ethics

Ethical approval was obtained from the local NHS ethics committee (Ref. No. 11/YH/0415).

Author contribution:

MAH conceived the idea. MAH and KM recruited patients. MAH analysed data under the supervision of MB, DPA and SJC. MAH prepared the first draft which was revised with intellectual input by MB, DPA and SJC. All authors have read and approved the final version.

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Table 1. Sociodemographic characteristics of the patients. Adapted and modified from (13)

ID	Age (Years)	Gender	Chronic pain duration in Years	Pain intensity (baseline)
P.1	36	Female	5-10	5
P. 2	49	Male	5-10	5
P. 3	63	Male	5-10	5
P. 4	30	Male	5-10	6
P. 5	74	Female	< 1	0
P. 6	58	Female	> 10	7
P. 7	39	Male	1- 3	7
P. 8	40	Female	< 1	7
P. 9	51	Male	3-5	10
P. 10	54	Female	3-5	7
P. 11	44	Female	1-3	5
P. 12	39	Female	> 1	8
P. 13	54	Male	5-10	10
P. 14	64	Female	> 10	5
P. 15	55	Male	3-5	9
P. 16	54	Female	1-3	6
P. 17	48	Female	>10	4
P. 18	27	Female	1-3	5
P. 19	47	Male	>10	7

Figure 1. Barriers to effective pain management

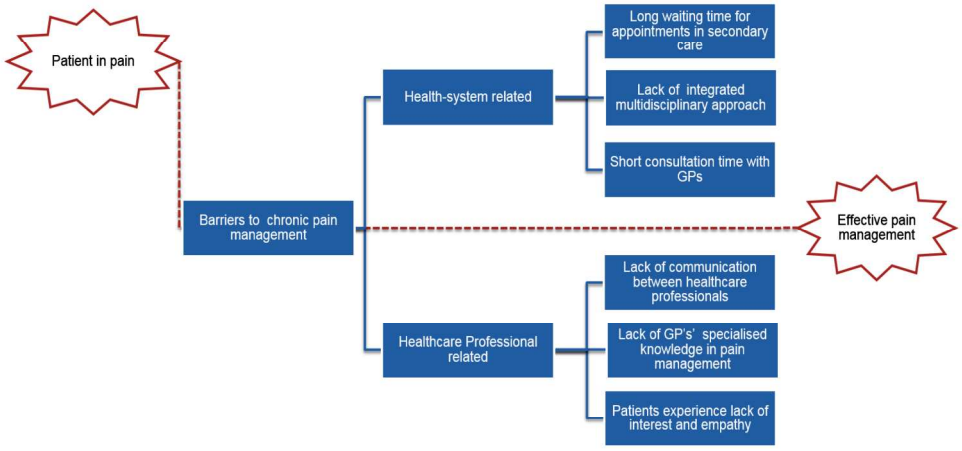

Figure 1. Barriers to effective pain management

273x153mm (300 x 300 DPI)

Topic Guide for Interviews*

Living with Pain

Tell me about how and when your pain started?

Has it affected your life in anyway?

Please explain how it has affected your life. (Explore the impact on various aspects of life)

Experience with pain management services

In general, how has been your experience with healthcare professionals in relation to pain management?

- Explore in particular experiences with GPs, physiotherapists and consultants.

How helpful did you find pain services?

Have you faced any issues/problems with these pain management services?

- Explore these issues further.

Expectations

What were your expectations from the pain clinic?

Have these changed now?

Has the care provided by NPMPC met your expectations? Disappointed?

Expectations of prognosis

Is this different from before?

Efficacy

Did it help?

What was the most helpful part?

How did it help?

Did they help you to manage problems with your pain medication?

Understanding and Self-management

Did it help you to understand your problem?

Was the information provided adequate?

Do you feel you have control over problem?

Do you think you can now manage your problem better on your own?

Interaction with Nurse and Pharmacist

Did they communicate well? Listened to your problem?

Did they encourage you to be active and self manage?

Did they give you enough time?

Have you had any problems in following their instructions?

Could they have done any better?

Anything particularly good or bad about the service?

Do you agree with their pain management approach?

* This topic guide was used for the larger-mixed methods study not particular for the findings reported in this paper. Other findings have been reported elsewhere (e.g. Reference 13)

Overall Satisfaction

Any other issues?

How do you think care could have been improved?

How do you compare it with other treatments?

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Methods (page 7)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Methods (page 7)
3. Occupation	What was their occupation at the time of the study?	Methods (page 7)
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	Methods (page 7)
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods (page 7)
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods (page 7)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods (page 6)
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods (page 6)
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods (page 6)
12. Sample size	How many participants were in the study?	Results (page 6)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A

Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods (page 6)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Results (page 25)
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods (page 7)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods (page 7)
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	Methods (page 6)
22. Data saturation	Was data saturation discussed?	Methods (page 6)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Methods (page 7)
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods (page 7)
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results (page 8-14)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Discussion (page 15-16)
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results (page 8-14)
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A

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"Treated as a number, not treated as a person": a qualitative exploration of chronic pain patients' perceived barriers to effective pain management

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"Treated as a number, not treated as a person": a qualitative exploration of chronic pain patients' perceived barriers to effective pain management

Muhammad Abdul Hadi, [*1] David Phillip Alldred,[1] Michelle Briggs,[2,3] Kathryn Marczewski,[4] S. José Closs[1]

[1]School of Healthcare, University of Leeds, Leeds, UK

[2]Division of Nursing, Midwifery and Social Work, School of Health Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK

[3]Research and Innovation Division, Central Manchester University Hospitals NHS Foundation Trust, Manchester, UK

[4]Clinical Nurse Specialist, Musculoskeletal Services, St. George's Centre, Leeds, UK

***Corresponding Author**

Muhammad Abdul Hadi

Research Fellow in Applied Health Research

School of Healthcare

Room 2.24 Baines Wing,

University of Leeds

Tel: 01133437558

Email: m.a.hadi@leeds.ac.uk

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Conflict of Interest: None declared.

Running head: Experiences of chronic pain management

Abstract

Objectives: To identify barriers to effective pain management encountered by chronic pain patients within the UK's National Health Service (NHS).

Design: Secondary analysis of face-to-face, semi-structured qualitative interviews using thematic analysis

Setting: A community-based chronic pain clinic jointly managed by a nurse and pharmacist located in the north of England.

Participants: Nineteen adult (>18 years) chronic pain patients discharged from a pain clinic, with the ability to understand and speak the English language.

Results: In general, patients were highly disappointed with the quality of pain management services provided both within primary and secondary care, and consequently, were willing to seek private medical care. Barriers to effective pain management were divided into two main themes: Healthcare professional-related and Health systems-related. Three sub-themes emerged under healthcare professionals-related barriers including: a) Healthcare professionals' lack of interest and empathy b) general practitioners' (GP) lack of specialised knowledge in pain management, c) lack of communication between healthcare professionals. Three sub-themes emerged under health system-related barriers: a) long waiting time for appointments in secondary care, b) short consultation times with GPs, c) lack of an integrated multidisciplinary approach.

Conclusions: The patients expressed a clear desire for the improved provision and quality of chronic pain management services within the NHS to overcome barriers identified in this study. An integrated holistic approach based on a biopsychosocial

model is required to effectively manage pain and improve patient satisfaction. Future research should explore the feasibility, effectiveness and cost-effectiveness of integrated care delivery models for chronic pain management within primary care.

Strengths and limitations of the Study:

- Qualitative research designs are best suited when patients' views and experiences are required to be explored.
- Various methods including peer-debriefing and in depth description of methods were used to ensure rigour and trustworthiness of study findings.
- The transferability of the study findings should be carefully considered as patients were recruited from one chronic pain clinic only, although patients were registered with different general practices and gave their views on NHS pain services in general.

Keywords: Barriers; Pain management; Chronic pain; Primary care; General Practitioners

Introduction

Chronic pain is one of the leading causes of disability globally (1). The prevention and/or effective management of chronic pain remains a serious challenge for public health authorities and healthcare systems around the world. It has been estimated that chronic pain affects 100 million adults in the US (2) and 28 million in the UK (3). Compared with patients with other chronic diseases, chronic pain patients tend to have poorer quality of life and use more healthcare resources (4-6).

Effective management of chronic pain is essential to limit its interference with sleep, work, physical and emotional functioning thus reducing the humanistic, societal and economic burden associated with this condition. Unfortunately, management of chronic pain remains suboptimal within primary care (5, 7). This is primarily because primary care services are often based on a 'biomedical model' rather than a 'biopsychosocial model', the latter being appropriate given the multidimensional nature of chronic pain (8, 9). Multidisciplinary clinics based on the biopsychosocial model have been shown to be effective and cost effective (8, 9). However, long waiting times for appointments, accessibility and affordability remain a serious concern (10).

The study reported here builds further on our existing knowledge of the issues and challenges faced by chronic pain patients especially within primary care settings (11). It describes findings from secondary analysis of qualitative data obtained during a mixed-methods study (12, 13). The main findings of the mixed-methods study are described elsewhere (13). The aim of undertaking this analysis was to identify barriers to effective pain management experienced by chronic pain patients within the UK's National Health Services (NHS).

Methods:

A qualitative description (14) design consisting of semi-structured, face-to-face interviews was used in this study. Qualitative description is commonly used by health service and practice researchers (14) as it is considered the method of choice when straightforward description of patients', caregivers', relatives' or healthcare professionals' experiences with a particular phenomenon is desired (14).

Sampling and recruitment

The interviews were conducted as part of a larger mixed-methods study which evaluated the effectiveness of a NHS nurse-pharmacist managed pain clinic (12, 13). The study design and working of the clinic have been described in detail elsewhere (13, 15). Patients who were enrolled in the quantitative phase of the mixed-methods study and discharged from the clinic within the study period were invited to participate in the interviews. A combination of two sampling techniques, convenience sampling and maximum variation sampling were used to recruit patients (16). Convenience sampling was used to recruit the first five patients and the remaining 14 patients were recruited using maximum variation sampling. The framework for maximum variation was based on: baseline pain intensity, duration of chronic pain and gender. Data collection continued until achieving ‘‘Data saturation’’ – whereby no new themes emerged from the data (16). Each interview lasted between 30 and 45 minutes. Written informed consent was obtained from all the study participants prior to the interview.

Data collection

Interviews were conducted by the first author, a research pharmacist trained in qualitative research, either in patients' homes or at the pain clinic, depending on the patients' preferences. To limit recall bias, all patients were interviewed within 2 weeks of their discharge from the clinic. Interviews were audio-recorded. A semi-structured interview schedule (Supplementary file 1) was developed based on the literature and study objectives to guide the interviewer and ensure uniformity. The interview schedule guide covered the following areas: patients' experiences of living with chronic pain (impact on physical functioning, sleep, emotions etc.); interaction with GPs/primary care physicians (PCPs) and other healthcare providers; experiences of the referral system; expectations of the pain clinic; efficacy of the service and overall experiences. Patients were also provided with an opportunity to talk about any other issue related to chronic pain that was not covered during the interview.

Data Analysis

Data were analysed using thematic analysis (14). A six-step process proposed by Braun and Clarke was used to guide the data analysis (17). Each interview was transcribed verbatim and transcripts were checked against the original recording for accuracy by the interviewer (MAH). This also allowed him to familiarize himself with the data. Line by line coding was used to code individual transcripts and the coding framework was checked independently by two experienced qualitative researchers for validity (MB, SJC). Duplicate codes were removed and different codes were sorted into potential themes. The relevant data extracts from individual interviews were gathered within these potential themes. Old themes were reviewed and sometimes renamed in the light

of the emergence of new themes. An illustrative example of data analysis is presented in figure 1. Methods such as peer review/debriefing and providing rich thick description were used to enhance rigour and trustworthiness of study findings (16).

Results

Nineteen patients were interviewed and their sociodemographic and clinical characteristics are shown in table 1. Emerging themes were classified under two overarching barriers: Healthcare professional related-barriers and Health system-related barriers (Figure 1). Sub-themes within each of these themes are described below, without any specific hierarchy/order.

Healthcare professionals-related barriers

Healthcare professional-related barriers included: lack of interest and empathy; lack of GP's specialised knowledge in pain management and lack of communication between healthcare professionals. Since chronic pain was predominantly managed in primary care, a number of the barriers in this category were related to the GPs' ability to assess and manage chronic pain (Figure 2).

a. Healthcare professionals' lack of interest and empathy

A number of patients expressed concerns over a perceived lack of interest shown by healthcare professionals, especially GPs, in listening to their problems and managing their pain. The patients felt that, as chronic pain was not a life-threatening disease (like, for example, cancer), healthcare professionals were not interested in identifying the cause of the pain. The patients were disappointed and felt that they were wasting their time in explaining their problem as no one was interested in listening to their problems.

A few of the patients felt that rheumatologists were only interested in listening to their initial problems, but not to their other ongoing problems, which sometimes might have been of more importance to the patients.

"I went to my GP and was just told it's wear and tear, age, nothing we can do about it, left it at that." [P.9, male]

"And then from rheumatology they don't listen to you, they don't… they listen to the initial problem and then they just do what they want to do." [Pt. 4, male]

Some patients felt that the GPs did not appreciate the negative impact of chronic pain on their daily lives and were very frustrated. A number of the patients felt they were disbelieved and judged by healthcare professionals. They were annoyed by these attitudes and this led them to stop seeking further treatment from that particular healthcare professional. Patients felt that they were treated impersonally, being passed from one healthcare professional to another.

"The second physiotherapist I saw basically told me that the pain was in my imagination. So I had one appointment with him. I'm in enough pain not to be able to tolerate people who are telling me it's not real, you know, because it is real. [P.10, female]

"……. because the way that they treat you is absolutely disgusting from point to point, there's no…… you're treated as a number, you're not treated as a person." [P.4, male]

However, some patients praised some GPs who listened to them and showed a duty of care towards them.

"… I don't feel as they've [GPs] just been giving me anything just to get rid of me, no they've been good."[Pt.16, female]

b. Lack of GPs' specialised knowledge in pain management

The main reason highlighted by patients, for GPs' inability to effectively manage chronic pain was a perceived lack of specialised knowledge in chronic pain management. The patients felt that the GPs do not have the right qualifications and skills to effectively manage chronic pain. Patients viewed GPs as having limited therapeutic options, with their approach towards pain management being confined to prescribing a range of analgesics, irrespective of whether the patients were gaining any benefit or not.

"I'm not saying my GP isn't qualified but he is a general practitioner, he's not a consultant and he's not specialised in that area." [P.6, female]

"…..According to them [GPs] all they could do was give me paracetamol, and the best was co-codamol." [Pt.9, male]

A few of the patients also felt that this lack of specialised knowledge was used as an excuse by the GPs to refer to the physiotherapist without establishing whether the patients actually needed physiotherapy or not.

"I think the GP finds it an easy… she doesn't know… it's the easy answer to shove you to the physio and let them have a look at you and then see what bounces back out of that." [P.4, male]

c. *Lack of communication between healthcare professionals*

Since the patients were referred to various specialists, they were concerned about the lack of communication between the different healthcare professionals, which often led to inconsistency in their approach towards pain management. The patients felt that a number of unnecessary referrals were made due to the lack of effective communication between healthcare professionals. These unnecessary referrals wasted both time and money and added to patients' frustration.

"I think you tend to see everybody in isolation. So the physio will refer and they will write a little letter and they will refer to a podiatrist. But then the podiatrist kind of sees the problem from such a different light that they're not really communicating with each other ……".[P.1, female]

"I went to the doctors, it's nothing. Tennis elbow, then it was arthritis, then it wasn't arthritis, then it was because of a previous injury. I came here, the

physiotherapist looked at the x-ray and couldn't understand why I'd been referred here." [P. 9, male]

In some instances the lack of communication led to a clash of opinions between the healthcare professionals and left the patient confused about their diagnosis.

"I was caught up in a bit of a battle between them two [Rheumatologist and Orthopaedic surgeon] because the rheumatologist was saying, no it's not a rheumatology problem and the orthopaedic guy was saying, well we believe it is." [P.15, male]

Healthcare system-related barriers

Healthcare system related barriers included: short consultation time with GPs; long waiting time for appointments in secondary care, and the lack of a holistic approach.

a. Short consultation time with GPs

Another problem frequently stated by patients was the short consultation time with GPs. This meant that the GPs could not listen to the patient's full story and therefore could not design an individualised therapeutic plan to meet their needs.

"It's the running of the GPs basically, we're not getting heard [Pause], patients aren't getting heard and listened to. There's not enough time [P.6, female]

"No sadly I don't think the GPs have enough time to look at each individual and to go through their medical history to see if they can tweak it here and there to help that patient. Sadly they haven't" [P.12, female]

In some cases, the patients felt that due to the limited consultation time, GPs just prescribed medicines as requested by them without obtaining a full history, putting them at high risk of experiencing an adverse or even life threatening event.

"The GP was worried about the high blood pressure but didn't take time to look at the medication she'd actually put me on, whereas the pharmacist pointed it out to her. Potentially according to the pharmacist, for three months, I was at high risk of having a stroke." [P. 9, male]

b. Long waiting time for appointments in secondary care

The patients were concerned over the long waiting times not only for appointments with consultants but also for scans, x-rays and other tests. The long waiting time delayed the whole care process. The patients felt that there were too many potentially avoidable, steps in the referral process, which contributed to their dissatisfaction with the service that they received from the NHS. In some instances, the patients remained for a long time under the care of their GPs without making any noticeable progress in terms of pain relief before being referred to a consultant/pain management service.

"You're going round the houses to get back to where you want to be. It takes a long time, it does take a long time." [P. 3, male]

"I was brought up to think that the Health Service would provide everything, but it doesn't, not quickly enough." [P. 5, female]

Since the patients were not happy with the long waiting time for the appointments in secondary care, they expressed their desire to go for private treatment, provided that they had the funds to meet the cost.

"……if I could afford it I'd go private, put it that way." [P. 4, male]

Patients who were able to afford it went on to seek care from the private sector and felt that the service provided there was much better than the NHS. As the patients had already paid into the NHS as taxpayers, they expected a good service from it. They were annoyed by the fact that they perceived the treatment was in fact better in the private sector, and they had to pay again to obtain this good service.

"I find the private sector, you know, service is much better. I do, I've found the NHS physio not very… [Pauses], if you are paying for treatment it is better, let's face it." [P.11, female]

"You wait so long in the [National] Health Service. But I had no alternative really except pay to see somebody, and that really rankles me, I don't want to do that. Because I've paid into it, haven't I? And my husband all these years." [P. 5, female]

c. Lack of integrated multidisciplinary approach

The set-up and the working of chronic pain management services in the NHS was seen as a hindrance in delivering integrated holistic care to patients. As chronic pain has a multidimensional impact on patients' lives, a unidimensional approach towards its

management based on the bio-medical model may not achieve optimum outcomes. The patients felt that they were not managed as a whole, but that specialists instead focused on only one of the affected areas or joints. Therefore, there was not only the lack of a holistic approach in terms of the working and integration of chronic pain services but also in terms of management of chronic pain patients.

"Within the NHS, every individual is great and they work really hard and they're really supportive, but they seem to be very caught in their little boxes and can't, or aren't allowed to, step outside them to maybe provide a more effective solution sometimes." [P. 1, female]

"He was not interested in any other joints, just the left elbow and I wanted them to look at all." [P. 9, male]

The patients stressed the need for a collaborative approach and believed that structural reforms were needed within the NHS so that it could better serve the needs of chronic pain patient population. However, the patients felt that the current situation of pain management services is unlikely to improve as the NHS is not willing to spend money to make the necessary reforms to improve chronic pain management.

"As well as the physical pain it can cause emotional problems and I think it's important to have a service where kind of all of that can be addressed together." [P. 18, female]

"I don't know whether that's a cost thing, whether arthritis is not a sexy disease like cancer or other things that the NHS want to throw money at." [Pt. 9, 51 years old male]

Discussion

The aim of this study was to explore chronic pain patients' perspectives on the barriers hindering the effective delivery of quality pain management services. Identifying such barriers could facilitate healthcare professionals and policy makers' ability to design and implement strategies to improve delivery of pain management services. This is especially important in front-line primary care settings, as access to adequate therapy has been declared to be a human right by various international resolutions (18,19).

In this study various healthcare professional and health system-related barriers have been highlighted. Since chronic pain is primarily managed within primary care, a number of themes revolved around GPs' ability to manage pain. In general, patients expressed considerable dissatisfaction with the quality of care provided by the NHS. However, it should be noted that patient satisfaction is primarily determined by patient expectations (20). A mismatch between patients' expectations and treatment outcome can lead to dissatisfaction. A systematic review reported that the best pain reduction intervention reduces pain, on average, only by 30% in about half of treated patients, meaning patients expecting cure or substantial reductions in pain are likely to be dissatisfied (21). Therefore, managing patients' expectations before and during treatment is critical in ensuring their satisfaction.

A common perception existed among patients that GPs lacked the specialised knowledge needed to manage chronic pain effectively. In studies from the UK and US, GPs/primary care providers (PCPs) have described helplessness and dissatisfaction with their own ability to manage chronic pain patients (22-24). This lack of confidence

may be explained by inadequate coverage of chronic pain in undergraduate medical curricula, highlighted in studies from the Europe and US (25, 26). Furthermore, significant increases in UK GPs' workload due to funding cuts in primary care services and difficulties retaining GPs within the NHS might also be compromising GPs' ability to effectively manage chronic pain (27). Between 2010/11 and 2014/15 face-to-face and telephone consultations grew by 13 and 63 percent, respectively. However, the GP workforce grew by only 4.75% during the same period (27). The ageing population, increase in the number of patients with multimorbidity and growing patient expectations are exacerbating these workload pressures (27).

A key concern expressed by patients was poor patient-professional partnerships due to lack of trust, empathy and communication. For patients with long term conditions, effective patient-physician relations can improve patients' health (28) and encourage self-management, key for chronic pain management. The lack of trust between patients and doctors may have negative impact on patient outcomes (28-30). Another key issue highlighted by the patients was the lack of interdisciplinary chronic pain services within the NHS. A need to reform chronic pain services within the NHS was also emphasised in order to facilitate the effective delivery of quality services. The UK's National Pain Audit found that of the 204 pain services evaluated, only 40% of clinics in England met the minimum criteria for multidisciplinary clinics by having a psychologist, a physiotherapist and a physician (31). The clinical and cost effectiveness of multidisciplinary clinics have been well documented in the literature (8,9), and therefore access to and affordability of multidisciplinary clinics should be made a priority to improve chronic pain management.

Patients were also concerned about the long waiting time for consultations in secondary care. The waiting time for six months or more from the time of referral to treatment is associated with a worsening of health-related quality of life and psychological wellbeing (32). The International Association for the Study of Pain (IASP) Task Force on Wait Times has recommended waiting times for urgent or semi-urgent and routine appointments to be within four and eight weeks, respectively (33). In the UK, prior to the publication of the core standards of pain management services by the Faculty of Pain Medicine, Royal College of Anaesthetics (34), in 2015, generic waiting times standards, usually 18 weeks, were being followed as reported in the National Pain Audit (31). The patients also felt that the lack of communication between healthcare professionals led to unnecessary referrals, adding to patients' frustration. This also partly contributed to the long waiting time for appointments in secondary care.

There are some limitations to our research findings. Firstly, since these findings have been drawn from the secondary analysis of qualitative data which were collected as part of a mixed-methods study, some of the barriers might not have been identified as the interview guide was not exclusively developed to explore barriers to effective pain management. However, as mentioned earlier, the interview guide had questions related to patients' experiences of healthcare services and interactions with healthcare professionals. Secondly, the generalisability/ transferability of study findings should be carefully considered as the data were collected from the patients discharged from a single community-based pain clinic and therefore may not necessarily reflect experiences of chronic pain patients living in other UK cities. However, the patients were referred to the pain clinic by different general practices within the catchment area.

Furthermore, the sample was quite diverse in terms of chronic pain conditions, duration of chronic pain, and pain sites.

Implications for practice and policy

The study findings have highlighted a perceived need to improve quality and delivery of healthcare services for chronic pain patients. Ideally, a national action plan involving all key stakeholders should be developed with the aim of improving access to and delivery of pain services within the National Health Service. Since chronic pain is primarily managed within primary care, there is a need to increase resources in this setting as a first step. Given the high workload for GPs, other healthcare professionals, such as nurses and pharmacists could be engaged in greater numbers in chronic pain management within primary care settings (13,35). Based on the findings of the present study and previously published literature, areas for improvement in terms of chronic pain management service delivery include, but not limited to: improving GPs' capacity to manage pain; engaging patients in decision making and promoting self-management; developing evidence based referral guidelines; improving communication between healthcare professionals and integrating existing services; and developing multidisciplinary pain clinics.

Conclusion:

The present study has identified a number of barriers to effective management of chronic pain. Given that access to adequate pain relief is a human right (18, 19), health policy makers should recognise suboptimal management of chronic pain as a serious public health issue and design multifaceted strategy to improve quality and delivery of chronic pain services. Identifying barriers should be seen as the first step to designing

more effective chronic pain services. Without having a clear vision, political will, and chronic pain as research priority, the current situation is unlikely to improve.

Ethics

Ethical approval was obtained from the local NHS ethics committee (Ref. No. 11/YH/0415).

Author contribution:

MAH conceived the idea. MAH and KM recruited patients. MAH analysed data under the supervision of MB, DPA and SJC. MAH prepared the first draft which was revised with intellectual input by MB, DPA and SJC. All authors have read and approved the final version.

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Table 1. Sociodemographic characteristics of the patients. Adapted and modified from (13)

ID	Age (Years)	Gender	Chronic pain duration in Years	Pain intensity (baseline)
P.1	36-40	Female	5-10	5
P. 2	46-50	Male	5-10	5
P. 3	61-65	Male	5-10	5
P. 4	26-30	Male	5-10	6
P. 5	71-75	Female	< 1	0
P. 6	56-60	Female	> 10	7
P. 7	36-40	Male	1- 3	7
P. 8	36-40	Female	< 1	7
P. 9	51-55	Male	3-5	10
P. 10	51-55	Female	3-5	7
P. 11	41-45	Female	1-3	5
P. 12	36-40	Female	> 1	8
P. 13	51-55	Male	5-10	10
P. 14	61-65	Female	> 10	5
P. 15	51-55	Male	3-5	9
P. 16	51-55	Female	1-3	6
P. 17	46-50	Female	>10	4
P. 18	26-30	Female	1-3	5
P. 19	46-50	Male	>10	7

Figure 1. Example of data analysis

Figure 2. Barriers to effective pain management

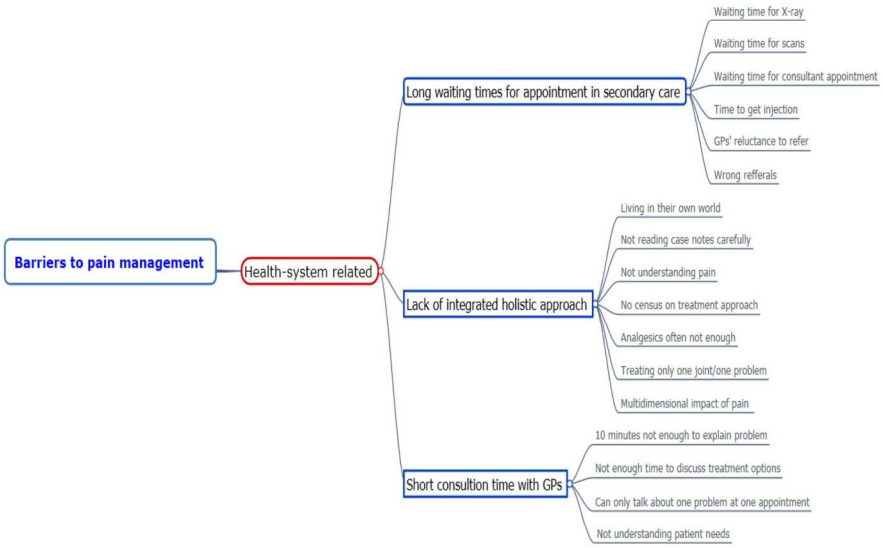

Figure 1: Example of data analysis

209x147mm (300 x 300 DPI)

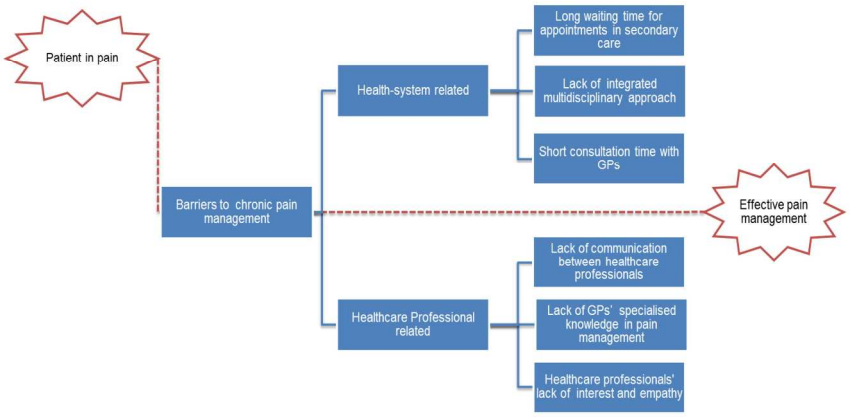

Figure 2: Barriers to effective pain management

297x209mm (300 x 300 DPI)

Topic Guide for Interviews*

Living with Pain

Tell me about how and when your pain started?

Has it affected your life in anyway?

Please explain how it has affected your life. (Explore the impact on various aspects of life)

Experience with pain management services

In general, how has been your experience with healthcare professionals in relation to pain management?

- Explore in particular experiences with GPs, physiotherapists and consultants.

How helpful did you find pain services?

Have you faced any issues/problems with these pain management services?

- Explore these issues further.

Expectations

What were your expectations from the pain clinic?

Have these changed now?

Has the care provided by NPMPC met your expectations? Disappointed?

Expectations of prognosis

Is this different from before?

Efficacy

Did it help?

What was the most helpful part?

How did it help?

Did they help you to manage problems with your pain medication?

Understanding and Self-management

Did it help you to understand your problem?

Was the information provided adequate?

Do you feel you have control over problem?

Do you think you can now manage your problem better on your own?

Interaction with Nurse and Pharmacist

Did they communicate well? Listened to your problem?

Did they encourage you to be active and self manage?

Did they give you enough time?

Have you had any problems in following their instructions?

Could they have done any better?

Anything particularly good or bad about the service?

Do you agree with their pain management approach?

* This topic guide was used for the larger-mixed methods study not particular for the findings reported in this paper. Other findings have been reported elsewhere (e.g. Reference 13)

Overall Satisfaction

Any other issues?

How do you think care could have been improved?

How do you compare it with other treatments?

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Methods (page 7)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Methods (page 7)
3. Occupation	What was their occupation at the time of the study?	Methods (page 7)
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	Methods (page 7)
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods (page 7)
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods (page 7)
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods (page 6)
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods (page 6)
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods (page 6)
12. Sample size	How many participants were in the study?	Results (page 6)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A

Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods (page 6)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Results (page 25)
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods (page 7)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods (page 7)
20. Field notes	Were field notes made during and/or after the inter view or focus group?	N/A
21. Duration	What was the duration of the inter views or focus group?	Methods (page 6)
22. Data saturation	Was data saturation discussed?	Methods (page 6)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Methods (page 7)
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods (page 7)
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results (page 8-14)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Discussion (page 15-16)
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results (page 8-14)
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A